

## Advance Care Planning for Individuals Experiencing Homelessness

In the United States and other industrialized countries, rates of disease and mortality are high among those experiencing homelessness.<sup>(1-3)</sup> In addition, the number of older adults without homes is expected to increase to 95,000 by 2050.<sup>(4)</sup> This growth is evident in Health Care for the Homeless programs, which have already seen a 51% increase in the number of patients age 50 or older between 2008 and 2014.<sup>(5,6)</sup> With these changing demographics coupled with poor health, there is a growing need for advance care planning (ACP) for this population, given its potential to prevent unnecessary suffering and to support an individuals' preferences related to care at end-of life.<sup>(7)</sup> This issue of *In Focus* provides a synthesis of recent literature on advance care planning among individuals experiencing homelessness. It gives an overview of morbidity and mortality of the homeless population, their concerns about death, advance care preferences, and implications for practice and policy.

### Morbidity and Mortality

High rates of disease exist in the general U.S. population. However, homelessness can contribute to poorer health outcomes by exacerbating existing conditions and creating new ones.<sup>(8)</sup> In particular, chronic health conditions such as diabetes, hypertension, and cardiovascular and lung diseases are common and rates of substance use disorders, mental illness, and infectious diseases are higher in this population (see Table 1).<sup>(2-3,10)</sup> Furthermore, the health of older adults without homes (age 50 and older) is comparable to the general elderly population (age 70 and over) with both groups at an

increased risk of developing chronic diseases and geriatric symptoms—"conditions that occur in older adults and cross discrete disease categories" (e.g., cognitive impairment, falls, and depression).<sup>(12-14)</sup>

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A lack of permanent housing, competing priorities associated with homelessness (e.g., food, shelter, and safety), high-risk behaviors (e.g., smoking and substance use), and barriers to health care services add to the complex challenges in managing these health issues. This may lead to further decline in overall health and ultimately result in a shortened lifespan and high mortality rates.<sup>(2,13,15)</sup> As shown by recent studies, mortality rates are estimated to be three-to-four times greater than the general U.S. population; and the average life expectancy is estimated to be 12 years less than the general U.S. population (66.5 vs. 78.8 yrs.).<sup>(16)</sup> Given the increased risk of disease and mortality in the homeless population, ACP should be facilitated earlier than for the general population.<sup>(14,17)</sup>

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*Table 1: Prevalence of specific health conditions among the homeless population in comparison to the general U.S. population.<sup>(2,8-9)</sup>*

Health Condition	Est. in Homeless Population	Est. in US
Hypertension	50%	29%
Diabetes	Up to 18%	9.3%
Myocardial infarction	35%	Up to 17%
HIV	Up to 21%	0.6%
Hepatitis C	Up to 36%	0.7%
Depression	Up to 49%	8%
Substance dependence	Up to 58%	Up to 16%

## Concerns about Death

Although there is little research about the concerns of death among individuals experiencing homelessness, limited data suggests that they have unique fears and experiences about end-of-life. Frequently reported concerns about death include but are not limited to:

- Fear of anonymous, unacknowledged, and unmemorialized death, which is associated with being distant or alienated from family members;
- Fear or thoughts that providers would not deliver appropriate care including withdrawing life-sustaining support or withholding symptom control treatments (e.g. pain medication), due to stigma associated with homelessness;
- Fear of what will be done with their bodies after death such as being cremated or used for experimentation; and
- Fear of a violent sudden death or a prolonged, painful, and lonely death.<sup>(1,18-19)</sup>

People without homes have also reported being exposed to death at an early age as well as to sudden violent deaths during bouts of homelessness, adding to current fears around death.<sup>(19)</sup>

## Advance Care Planning

According to the National Hospice and Palliative Care Organization, ACP is a process through which decisions are made about the care one would want to receive in the event of being unable to speak for oneself. It includes learning about options for life-sustaining/saving treatments, making those decisions ahead of time, letting loved ones know about advance care preferences, and documenting preferences, often in a legally binding document.<sup>(20)</sup>

Patients may document their preferences for advance care and surrogate decision-makers through advance directives such as living wills, durable power of attorney, do-not-resuscitate orders and Physician Orders for Life-Sustaining Treatment (POLST). However, these can also be consolidated into one “go-to” document for health providers.<sup>(9)</sup> This “go-to” document is generally stored in medical records at the site at which it was completed and, with the patient’s permission, can be filed elsewhere such as at county and Veteran Affairs hospitals. For this marginalized population, this type of documentation has been demonstrated to be very valuable.<sup>(21)</sup>

## Palliative and End-of-life Care

The terms “palliative” and “end-of-life care” are often used interchangeably, as both provide patient- and family-centered care that aims to alleviate symptoms and optimize quality of life. However, palliative care may be given alongside curative treatment plans to individuals with life-threatening or complex illnesses; whereas end-of-life care is given without curative treatment to individuals with a life-limiting prognosis (i.e., given a life expectancy of six months or less).<sup>(9,22)</sup>

Although the number of advance care programs has increased over the years, these services remain mostly inaccessible to individuals experiencing homelessness.<sup>(9,15)</sup> Research has established four major categories of barriers to advance care: personal, structural, financial, and provider willingness and knowledge (see Table 2). Combined, these barriers too often result in persons experiencing homelessness dying without appropriate health care support and without ever accessing advance care programs.<sup>(15)</sup>

Table 2: Barriers to advance care planning for individuals experiencing homelessness.<sup>(12,14,17,22,24)</sup>

## PERSONAL

- Prioritization of meeting basic needs for day-to-day survival
- Denial of death and dying and/or discomfort in discussing topic
- Spirituality and religion shapes perceptions of life and death; feeling that end-of-life is in the hands of a higher power
- Reluctance to access advance care services due to prior negative experiences with the health care system, or fear of being burdensome or undeserving of care
- Lack of understanding or misconceptions of key terminologies (e.g., palliative care, surrogate decision-making, vegetative states, and heroic treatments)

## STRUCTURAL

- Lack of housing
- Strict rules and regulations of existing housing programs exclude those not functionally independent and who are ongoing substance users
- Strict rules and regulations of hospice and hospital-based end-of-life care programs exclude ongoing substance users
- Lack of continuity of care (i.e., lack of follow-up and poor discharge planning)
- Limited number of palliative and end-of-life programs for those who have low-incomes and/or are uninsured

## PROVIDER

- Lack of clear process of advance care planning
- Lack of sufficient reimbursement
- Lack of knowledge of providing palliative or end-of-life care
- Discomfort in discussing end-of-life topics with patients
- Concerns about legal implications of advance care documents and interpretation
- Preconceptions or stereotyping of persons without homes

## FINANCIAL

- Insufficient funds to pay out-of-pocket for end-of life care or burial plan
- Limited or no insurance coverage
- High cost of providing palliative and end-of-life care

## Advance Care Preferences and Attitudes

Few studies have assessed the end-of-life preferences of people experiencing homelessness and the effect of ACP interventions on patient attitude. Participants in these limited studies were able to identify: surrogate decision-makers and preferences for symptom control, life-saving/sustaining treatments, and care of their bodies after death.<sup>(13,21,24)</sup> For example, a recent study by Leung et al. (2015) revealed that most participants prefer to receive cardiopulmonary resuscitation (CPR) if they had a chance of returning to their current state of health. However, preference to receive CPR declined when presented with hypothetical situations of returning to dementia or permanent comas. In the same study, a majority of participants reported that completing an advance directive helped them feel at peace and think more about their health, family and friends.<sup>(24)</sup>

Despite being distant or alienated from family members, participants without homes across two studies identified a family member as a surrogate decision-maker.<sup>(21,24)</sup> However, in other studies some participants preferred not to have family members involved in making decisions or even to be contacted in the event of death or unconsciousness, instead listing friends and medical and non-medical homeless service providers as surrogates.<sup>(1,18)</sup> In a qualitative study by Ko et al. (2014), older adults without homes reported having a preference for physicians to be surrogate decision-makers because they trusted their medical expertise in the absence of family and social support. These studies demonstrate that preferences for advance care can vary greatly. Whether one prefers closure and comfort care, aggressive treatment up to the time of death, or involving medical providers or family members in final decisions, written documentation is key to preserving control over care.<sup>(9)</sup>

## Implications

This literature review demonstrates a high level of adverse outcomes (premature mortality and insufficient care at end-of-life), especially for adults age 50 and older as well as those with complex or life-threatening illnesses. The inability to pay out-of-pocket for palliative and end-of-life care is also common and may contribute to a death without comfort and dignity. More intensive,

tailored approaches to advance care may be needed for individuals who have difficult histories and minimal family and social support.

## Practice implications

A number of promising practices for advance care have emerged over the past few years, including shelter-based palliative care and medical respite programs.<sup>(25,26)</sup> In addition, various strategies in advance care planning have been suggested to address the unique circumstances of this marginalized population. One of these strategies is the utilization of trained staff to provide guidance through the ACP process, as studies have shown that participants experiencing homelessness are more likely to complete ACP activities if intensive support is provided.<sup>(21,24)</sup> Additionally, these participants have suggested a number of ways in which the ACP process can better meet their needs including:

- 1) Increasing positive interaction between the health care system and individuals experiencing homelessness;
- 2) Considering unique issues confronting individuals experiencing homelessness;
- 3) Diversifying care delivery methods; and
- 4) Increasing availability of advance care services (see Table 3)

In regards to policies around ACP, the Patient Self-Determination Act passed in 1990 requires Medicare and Medicaid providers to be educated about patient self-determination and advance directives and to periodically inquire about any existing advance directive or other form of document regarding their patients' medical care wishes. However, it does not require providers to assist in completing an advance directive.<sup>(9)</sup> Starting in 2016, Medicare will reimburse providers for ACP services<sup>(27,28)</sup>, and while this helps alleviate the financial barriers for providers, it should be noted that only a small percentage of people who are homeless are Medicare beneficiaries.<sup>(29)</sup>

**Table 3: Suggestions to better meet the needs of individuals experiencing homelessness in advance care.** <sup>(1,12,18,22)</sup>

Issue	Suggestion	Examples of solutions
Many individuals experiencing homelessness mistrust the health care system due to past negative experiences	Increase positive interaction between health care system and individuals experiencing homelessness	Train health care staff on providing compassionate care and remove preconceptions and stereotypes
Individuals face a number of competing priorities  Without family and social support, some fear an anonymous death	Consider unique issues confronting individuals experiencing homelessness	Coordinate with other social services to better meet needs  Use body features like scars and tattoos to help in recognition and removing anonymity
Limited availability of palliative and end-of-life care services  Those existing have strict rules and regulations that seem to exclude this population  Individuals experiencing homelessness may want to access advance care in different settings	Increase availability and diversify advance care delivery methods	Meeting individuals where they are such as in shelters, on the street, in medical respite programs, or in permanent supportive housing  Adapting a low threshold strategy- having minimal admission requirements  Integrating harm reduction strategies for substance users

## Recommendations

To better understand the effectiveness of ACP on homeless populations and to ensure positive outcomes, the following actions are recommended:

- It is important for providers to acknowledge the realities faced by patients experiencing homelessness and introduce ACP in a safe context and over repeated visits, building rapport and trust;
- It is important for stakeholders to consider and agree to a location within the patient medical record where ACP will reside, and establish procedures for when it is to be used and/or shared;
- Studies are needed to increase understanding of the clinical outcomes, cost-effectiveness, and implementation of advance care programs tailored for people experiencing homelessness such as those that exist in medical respite and permanent supportive housing programs; and
- Improvements in Medicaid and Medicare coverage of advance care (palliative and end-of-life care) are needed for people experiencing homelessness with terminal or complex illnesses.

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